Quality of Life Research

A Critical Introduction

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APOLOGIA

Let us begin by seeing the assessment of quality of life in practice. In the extracts below, transcribed from recordings of the administration of Schalock and Keith's (1996) *Quality of Life Questionnaire*, we see how the moment-by-moment interaction of quality of life assessors and assessees produces scores on a standardized QOL measure.[1] Each question has three response options, scored 1, 2 and 3.

Extract 1

Interviewer	D'you feel out of place out an' about in social situations?
Anne	No
Interviewer	Anne? Never?
Anne	No
Interviewer	Sometimes?
Anne	No
Interviewer	Or usually?
Anne	Sometimes I do
Interviewer	Yeah? OK, we'll put a two down for that one then

Extract 2

Interviewer	Oh right, OK then, right then, so Arthur would say that your life brings out the best in you?
Arthur	Brings out the best in you
Interviewer	Or treats you like everyone else?
Arthur	Anybody else
Interviewer	Or doesn't give you a chance?
Arthur	Uh er treats yer uh uh all alright
Interviewer	The same as everyone else? You the middle one?
Arthur	Yeers.

These sorts of exchanges, typical of the administration of *any* quality of life questionnaire (Houtkoop-Steenstra, 2000), suggest that assessment of quality of life – whatever the designers of questionnaires, or the writers of survey manuals, say – is, *in practice*, far from straightforward.

If we are to get a firm grip on quality of life research, and become informed practitioners, we need to be aware of both the positive findings, persuasive theories and impressive-looking measures, and also of the practical and theoretical difficulties inherent in the ideas, concepts and assessment methods of the area. This book introduces – and offers a critical reflection

upon – social scientific research on QOL, outlining those persuasive theories, impressive measures and positive findings, but also warning against uncritical acceptance. The intention is to equip students with an understanding of the main approaches to quality of life research, and the conceptual-analytic tools needed to become discerning 'consumers' of the literature. Much of this book is designed to *show*, as well as *tell*, how such a critical engagement might proceed. To support the development of a critical stance, each chapter ends with study questions.

We take as a guide Michel Foucault's (1985: 8) observation on the purpose of knowledge:

> What would be the value of the passion for knowledge if it resulted only in a certain knowingness … and not, in one way or another … in the knower's straying afield from himself … the question of knowing if one can think differently than one thinks, and perceive differently than one sees, is absolutely necessary if one is to go on thinking and reflecting at all.

We'll put a two down for that one then.

Note

1. Data are drawn from Rapley and Antaki (1996). Transcription is simplified.

PREFACE

> quality *n*. 1. a characteristic, property or attribute. 2. high grade; superior.
> of *prep*. A particle indicating 5, a relation of identity.
> life *n*. 1. Condition which distinguishes animals and plants from inorganic objects and dead organisms … 5, course or mode of existence.
> (Macquarie Dictionary, 1992)

In 1990 the leading ethnographer of the lives of people with intellectual disabilities,[1] Robert Edgerton, suggested that the term 'Quality of Life' was the 'shibboleth of the 1990s' (1990: 149). The term 'shibboleth' implies not only the importance of the concept, but also the contentious nature of the field and the potential upshot of QOL research. In public life, and the social sciences, the notion of QOL has come – since the 1960s – to be a routinely invoked concept. The term appears in the discussion of everything from the relative 'liveability' of towns, cities and nations to the aims and effects of social policy, from the relative benefits of differing models of human service provision to the individualized outcomes of a vast number of medical and psychotherapeutic practices.

This is not to suggest that questions about what constitutes a life of quality, or what the characteristics, properties or attributes of such a life might be, only began in the 1960s. As Socrates famously noted, the unexamined life is one unworthy of living (Plato, 1903). Much of Western philosophy and literature since can be read as an extended response to his questions about life's quality and qualities. While some might dismiss such endeavours as frippery produced in 'a playground for philosophical speculation' (Veenhoven, 1997), the upshot of such questioning has always been practical and serious – both historically and in the present. The Nazi conceptualization of a life of quality entailed the idea of 'life unworthy of life' – an idea that warranted the 'euthanasia' of people with intellectual disabilities, the chronically ill, and the inmates of mental hospitals by German doctors and psychiatrists in the 1930s and 1940s (Gilbert, 1986: 239). Currently, the idea that it is possible to *quantify* the *quality* of a life – to establish numerical parameters for the relative value of lives with particular qualities – is a warrant for the selective abortion of particular foetuses (Kuhse and Singer, 1985), the provision (or not) of life-sustaining medical interventions (Nord, 1999) and, in some jurisdictions, 'physician-assisted suicide' for those whose quality of life is 'pointless and empty' (Sheldon, 2000: 1174).

It is in the contemporary social sciences that the most sustained efforts

have been made to define, describe and understand quality of life. In their 1996 literature review Antaki and Rapley (1996a) identified over 2,500 journal articles specifying 'quality of life' as a keyword in the preceding three years. Hughes *et al.*'s (1995) survey identified 44 separate definitions between 1970 and 1993. Cummins (1997a: 1–2) noted 'well in excess of 100 definitions and models … some are clearly representative of others while some are cast in such vague or inclusive terminology that their heuristic value approaches zero'. The electronic archives of the *British Medical Journal* identify 702 articles with 'quality of life' in their titles between 1994 and 2001. Muldoon *et al.* (1998: 542) state that 'over 1000 new articles a year are indexed under "quality of life"'. Entering 'quality of life' into Google returned no fewer than 'about' 3, 410, 000 webpages! QOL is, evidently, a concept of powerful – if not pervasive – resonance in contemporary life. Yet the very popularity of the concept (and use as a 'lay' rather than 'technical' term) has resulted in a fragmented literature. The literature is, furthermore, a site of considerable controversy over issues ranging from the adequacy of QOL as a scientific construct, to the meaningfulness of QOL measurement and the social policy relevance of QOL measures.

To add to the confusion the various social scientific literatures conduct their own QOL debates in isolation from each other, and sub-areas within each field show little appreciation of work in adjacent specialisms. In the developing field of health-related QOL (HRQOL) separate, and condition-specific, measures of HRQOL exist for almost every problem for which there is a medical specialty. Multiple QOL measures exist for kidney disease and end-stage renal failure specifically (Cagney *et al.*, 2000; Wu *et al.*, 2001; Martin and Thompson, 2001); for acne (Klassen *et al.*, 2000; Martin *et al.*, 2001); for head and neck cancer (Hammerlid and Taft, 2001); for respiratory disease (De Vries *et al.*, 2000) – with a number of asthma-specific measures (Ehrs *et al.*, 2001); for epilepsy (Ergene *et al.*, 2001); for vertigo (Prieto *et al.*, 1999); and for genital herpes (Spencer *et al.*, 1999). There are even QOL measures to assess the QOL of parents whose children have problems – for instance toddlers with motor disorders (Hendriks *et al.*, 2000).

Given such fragmented – often contradictory – literatures there is, says leading QOL researcher Bob Cummins, no hope of a comprehensive overview. He suggests that 'the literature is now too vast for any individual researcher to fully assimilate' (1997b: 118). Hence this book is selective. QOL is placed in its historical and cultural context; concepts underpinning QOL as a global construct are outlined; definitional controversies and commonalities across disciplines are discussed; and an introduction to key evaluative methods and tools – purpose, potential and limitations – across a range of sites is provided. My approach to the identification of exemplary studies – or, as it lacks the connotation of excellence, *illustrative* studies – is guided by Silverman's (1997) recommendation that *aesthetic criteria* be accorded a central place in the evaluation of social scientific research.

> […]volumes have been written about how theoretical or political positions (either implicit or explicit) shape the research task … Such positions have relatively little to do with many researchers' sense of what constitutes a 'worthwhile' research problem, 'interesting data' or a 'compelling' analysis … I believe that the most important impulse has more to do with our tacit sense of the sort of appearance or shape of a worthwhile piece of research. In that sense research is informed by an aesthetic. (Silverman, 1997: 239)

Accordingly I discuss pieces of research that offer what ethnomethodologists would describe as *perspicuous instances*. That is, work discussed has been selected by virtue of its capacity to illustrate with clarity, simplicity and economy (cf. Wittgenstein, 1961) major conceptual and methodological issues in QOL research. Each chapter concludes with suggestions for further reading, and a list of questions for further study. The Resources section (Appendix 3 page 249) lists sites providing starting points for further research, journals to consult and texts which provide more detailed guidance on various research approaches.

The book is divided into two parts: In Part 1, Chapters 1–3 offer a critical overview of key philosophical, conceptual and methodological issues. These chapters draw widely on QOL literatures across disciplines and population groups. Chapter 4 offers a review of methodological issues in quantitative and qualitative QOL research, with a discussion of the strengths and weaknesses of the principal methodological tools. The promises and pitfalls of these methods are illustrated with reference to specific QOL instruments and research approaches. Part 2 illustrates the application of the principles, concepts and methodologies discussed in Part 1. These chapters demonstrate work at a range of levels – from the analysis of social policy to service outcome research – with reference to population groups where QOL research is most developed. These chapters offer 'worked examples' of QOL research, and illustrate the diversity of approaches to the topic. The aim is, after Wittgenstein, a 'showing' rather than a 'telling'. The areas covered highlight controversial issues identified in Part 1. Thus, discussion of the adequacy of QOL as a scientific construct in Chapter 2 is picked up in Chapter 5 by an illustration of how the work of Foucauldian thinkers offers a deeper appreciation of the relationship between social scientific studies of QOL and their cultural context. Chapter 6 unpacks the ethical debate in Chapter 3 by a detailed analysis of HRQOL research. The discussion of conceptual issues in the development of generic versus population-specific QOL measures in Chapter 4 is illustrated in Chapter 7 by empirical work on these topics. Chapter 8 analyses recent developments in the psychological literature and Chapter 9 offers a recapitulation of the main themes and a response to criticisms of the philosophy, theory and practice of QOL research in the literature. Directions for research are identified.

Note

1. I use the term 'intellectual disability (-ies)' to refer to people also known as people with learning difficulties (UK) and people with mental retardation (USA).

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Note

This book draws on some of my earlier work and extends analyses previously published. Chapter 3 draws on Rapley, M. (2001) Policing Happiness, in Newnes, C., Holmes, G. and Dunn, C. (eds) *This is Madness Too*. Ross-on-Wye, PCCS Books and McHoul, A. and Rapley, M. (2002) "Should we make a start then?": A strange case of a (delayed) client-initiated psychological assessment, *Research on Language and Social Interaction*, 35, 1: 73–91. Chapter 4 draws upon Antaki, C. and Rapley, M. (1996). Questions and answers to psychological assessment schedules: hidden troubles in 'Quality of Life' interviews, *Journal of Intellectual Disability Research*, 40, 5: 421–37; Rapley, M., Ridgway, J. and Beyer, S. (1998) Staff:staff and staff:client reliability of the Schalock and Keith (1993) Quality of Life Questionnaire, *Journal of Intellectual Disability Research*, 42, 1: 37–43. Chapter 5 extends Rapley, M. and Ridgway J. (1998). Quality of Life talk: the corporatisation of intellectual disability. *Disability and Society*, 13, 3: 451–71. Chapter 9 develops Antaki, C. and Rapley, M. (1996). "Quality of Life" talk: The liberal paradox of psychological testing. *Discourse and Society*, 7, 3: 293–316 (by the kind permission of Sage Publications Ltd 1996).

This book is for Ella and Tom.

PART ONE – THEORY

CHAPTER 1

Introduction – Where Has QOL Come From?

> My nominee for the key issue in the study of language and the brain during the first century of the third millennium is a concept that is slippery, burning, neglected, and crucial. That concept is definition and measurment of quality of life. (LaPointe, 2001: 135)

> The quality of life construct has a complex composition, so it is perhaps not surprising that there is neither an agreed definition nor a standard form of measurement. (Cummins, 1997a: 6)

This chapter offers a historical overview of the development of the concept of 'quality of life' in both public life and as an object of study in the social and human sciences. Drawing extensively on the work of Kenneth Land, Heinz-Herbert Noll and Michael Salvaris, I outline the development of the QOL construct, from being a social scientific index of the relative well-being of whole populations (a measure of the state of states) to being a measurable aspect of individual subjective experience (an index of the state of persons). The intention is not to produce a 'Whig' history[1], but to examine the relations between ideas of what QOL might be across what are usually termed 'levels of analysis': that is as a property of both individual persons *and* human collectivities.

QOL as the State of States

It is important to begin by placing the idea of quality of life (or QOL) into historical context. To do so we must suspend both our ordinary or commonsense understandings of what the term 'quality of life' means, and also formal operational definitions of the idea in the social scientific literatures (see Kendall and Wickham, 1999: chapter 1). For, as Mike Salvaris (2000: 4) suggests in his account of the social indicators movement in Australia:

> Political economists from Hobbes to Marx have observed that 'the most powerful instrument of political authority is the power to give names and to enforce definitions' (Chorover, 1979); and in western society since the Industrial Revolution, there has been no more potent idea to be defined (and thus harnessed) than the idea of progress. This idea, with its connotations of destiny and inevitability, has become almost 'the meta

> narrative of history' (McLintock, 1992) – legitimating political power, elevating those who define and interpret it, and providing a unifying theme for the policies of nations.

Writing in 1996, Veenhoven suggested:

> 'In the first half of this century, quality-of-life in nations was largely measured by the material level of living. The higher that level in a country, the better the life of its citizens was presumed to be … quality-of-life was measured by GNP related measures, currently by 'real' GDP per head … Yet in the 1960's, the opinion climate changed … This gave rise to a call for broader indicators of quality-of-life, which materialized into the so called 'Social Indicator' movement. (Veenhoven, 1996: 1)

While accurate in terms of its chronology, such an account – falling as it does into historicist fallacy – shows just how 'slippery' the notion of QOL can be. Clearly, if in the first half of the twentieth century it was the GNP, or 'the material level of living', that was gauged, then it was not 'quality of life' that was being measured. What Veenhoven's account suggests then is that it is possible – as indeed he himself points out later in his paper – to (re)define (or 'give a name to' as Chorover put it) almost *any* social statistic or collection of social statistics as 'QOL'.

Cummins attributes the coining of the term quality of life in its 'modern form' as a characteristic of persons *as well as* an indication of national prosperity, to a 1964 speech by President Johnson in which he is reported to have stated that *progress* on social goals 'cannot be measured by the size of our bank balance. They can only be measured by the quality of the lives our people lead' (Cummins, 1997b: 117). Similarly Noll (2000) suggests that: 'as early as in 1964 former U.S. President Lyndon Johnson stated: "the great society is concerned not with how much, but with how good – not with the quantity of goods but with the quality of their lives"'. The idea of quality of life as a measurable indicator of the 'great society's' achievements has, since its inception, been inseparable from the notion of progress. With an elegant symmetry, in the social sciences, as in political economy, 'the most powerful instrument of [political] authority is the power to give names and to enforce definitions'.

The development of a 'modern', or *individualized*, notion of QOL was neither immediate nor inevitable. Noll (2000) points to the development of two contrary conceptualizations of quality of life, one being a Scandinavian view based in the works of writers such as Drenowski (1974), Erikson and Uusitalo (1987) and Erikson (1993), centred on notions of the 'good society' and of social well-being as a welfare issue. In this work welfare is conceived of as based in access to resources by which people can control and direct their 'level of living' and, in the provision of which, public policy may have leverage. Erikson and Uusitalo (1987: 189) specify the resources citizens require in order to secure their own welfare:

'resources are defined in terms of money, property, knowledge, psychic and physical energy, social relations, security and so on'. In consequence Scandinavian thinking focuses exclusively on *objective indicators* of the level of living, or quality of life, of society as a whole.

However, as Noll notes, what he terms 'the American quality of life' approach commands more of a consensus in the 'Western' world. In this model, quality of life research – or welfare measurement – is primarily based in the assessment of *subjective indicators* at the level of individual citizens. Noll (2000) suggests of the 'American' model that

> in the tradition of the utilitarian philosophy and 'mental health research' … this approach ultimately defines welfare as subjective well-being. The most important indicators of subjective well-being used, actually, are measures of satisfaction and happiness.

So where has the idea of 'quality of life' come from? Along with Cummins, Veenhoven and Noll, Land (2000) locates the beginnings of QOL in the 'social indicators movement' of the 1960s. The impetus, it is claimed, was the joint efforts of a NASA and the American Academy of Arts and Sciences project to predict the societal effects of the space race (Land, 1983; Noll and Zapf, 1994). Noll (2000) describes the origin of the movement thus:

> […] social indicators research was created in the United States in the mid-1960s … The project came to the conclusion that there was almost a complete lack not only of adequate data but also of concepts and the methodology for this purpose. Presumably it was Raymond Bauer, the director of the project, who also invented the term and concept of 'social indicators' [Bauer, 1966: 1]. In his definition, social indicators were 'statistics, statistical series, and all other forms of evidence that enable us to assess where we stand and are going with respect to our values and goals'.

Land (2000) points out that what came to be called the 'social indicators movement' by 1969 had much earlier progenitors. Carley (1981) has suggested that large scale formalization of interest in measures of the state of states was part of a broader trend towards the organization of national social, economic and demographic information that began in Western societies during the Enlightenment. This trend was consolidated through the seventeenth and eighteenth centuries and accelerated dramatically over the course of the twentieth century. Such a view resonates with Foucault's work (1973, 1977, 1978) on the rise of governmentality, surveillance and the individual subject in the emerging nation states over the same period. It is regrettable that while much current societal-level QOL work appreciates its own political relevance (for example, Veenhoven (1996) considers that his proposed measure of 'Happy Life Expectancy'

(HLE) would have 'political appeal'), most leading QOL researchers are dismissive of poststructuralist readings of the development of social indicators and their transformation into devices of individual surveillance (Cummins, 2001a).

Early in the development of such indicators Land (1975) points to the activities of the Chicago school in the 1930s and 1940s, specifically the work of Ogburn on the theory and measurement of social change and his responsibility for the production, in 1933, of *Recent Social Trends in the United States*. Noll (2000) identifies the work of Drenowski at the United Nations on systems of social indicators in the 1950s as an early contribution to the project of improving the 'measurement of the level of living by identifying components of welfare and by constructing respective indicators' (Noll, 2000). By 1969 the future direction of health economic uses of social indicators had been anticipated, as had one of the key individual-level uses of the notion of quality of life. Gudex (1990) identifies the publication by Klarman *et al*. (1968) of a cost-effectiveness analysis of chronic renal disease treatment as the beginning of the QALY (quality adjusted life year) movement in medicine (of which more in Chapter 6).

At the societal level, in 1969 the US Department of Health, Education, and Welfare document *Toward a Social Report* identified health and illness; income and poverty; the physical environment; public order and safety; social mobility; learning, science and art; and participation and alienation as key social indicators (USDHEW, 1969). The definition of a 'social indicator' in this document is attributed by Land (2000) to the economist Olson – namely a 'statistic of direct normative interest which facilitates concise, comprehensive and balanced judgements about the condition of major aspects of a society' (USDHEW, 1969: 97). In all cases, Land argues, Olson viewed such indicators as direct measures of welfare which afforded the conclusion that, if changes occurred in the right direction, all else being equal, things have improved, or that people could be understood to be 'better off'.

Both Noll and Land attribute the rapid international diffusion of social indicators work to the social and political climate of the 1960s and 1970s. Noll (2000) suggests that while this was a period of prosperity, it was also a period when questioning of economic growth as the major goal of public policy and the primary indicator of social progress began. This questioning has, more recently, again become a pressing political issue with the development of anti-globalization protest movements. Noll argues that, during this period: 'there was increasing doubt whether more should ever equal better … The concept of "quality of life" was born as an alternative to the more and more questionable concept of the affluent society and became the new, but also much more complex and multidimensional goal of societal development' (Noll, 2000). Land's (2000) description of the flurry of activity at this time – which depended on widespread acceptance of